

House Resolution

No. 6

**Introduced by Assembly Member Achadjian
(Coauthor: Assembly Member Mullin)**

February 2, 2015

House Resolution No. 6—Relative to Rare Disease Day.

1 WHEREAS, There are nearly 7,000 diseases and conditions
2 that are considered rare, each affecting fewer than 200,000
3 Americans; and

4 WHEREAS, Of these 7,000 rare diseases, more than 80 percent
5 are considered ultra rare, affecting less than a few thousand
6 Americans; and

7 WHEREAS, While each of these diseases may affect small
8 numbers of people, rare diseases as a group affect almost 30 million
9 Americans; and

10 WHEREAS, Many rare diseases are serious and debilitating
11 conditions that have a significant impact on the lives of those
12 affected; and

13 WHEREAS, While more than 400 orphan drugs and biologicals
14 have been approved for the treatment of rare diseases affecting up
15 to 14 million people, according to the United States Food and Drug
16 Administration, millions of Americans affected by rare diseases
17 have no treatment specific to their disease; and

18 WHEREAS, Besides dealing with their specific medical
19 problems, individuals and their families affected by these rare
20 diseases struggle with obtaining accurate and timely diagnosis,
21 few treatment options, and accessing or being reimbursed for
22 treatment; and

1 WHEREAS, While some rare diseases are relatively well known,
2 many others are not known at all by the public, making patients
3 and their families bear a large share of the burden of fundraising
4 and research; and

5 WHEREAS, Nearly one in 10 Americans has a rare disease,
6 and a large number of Californians are among those affected by
7 those diseases; and

8 WHEREAS, Research into rare diseases and development of
9 therapies builds greater understanding of the nature of disease and
10 serves as a foundation for innovation in the United States; and

11 WHEREAS, A nationwide observance of Rare Disease Day
12 will take place on February 28, 2015, when patients, medical
13 professionals, researchers, government officials, and companies
14 developing treatments for rare diseases will join together to focus
15 attention on rare diseases as a public health issue; now, therefore,
16 be it

17 *Resolved by the Assembly of the State of California*, That the
18 Assembly proclaims February 28, 2015, as Rare Disease Day in
19 California; and be it further

20 *Resolved*, That the Chief Clerk of the Assembly transmit copies
21 of this resolution to the author for appropriate distribution.